Kidney

FALL & WINTER 2023
MAGAZINE

VOLUME 1(1) | Fall & Winter 2023

PHYSICAL ACTIVITY VS EXERCISE

Enjoy these easy and fun ways to get moving

MEATLESS MONDAYS

Cooking your way to improved kidney health

NEWLY DIAGNOSED?

What you need to know, and what you can do

SYLVIE CHARBONNEAU

Up close and personal with a living donor and Transplant Games medal winner

CARING FOR CARE PARTNERS

It’s okay to take a break

kidney FOUNDATION™

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Kidney
FALL & WINTER
MAGAZINE

Fall & Winter 2023 | Volume 1 Issue 1

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letter from the editors

Dear reader,

It is with great pleasure that we present to you the inaugural issue of The Kidney Foundation of Canada, BCY Branch's *Kidney* magazine. As the editors, we are thrilled to bring this publication to life, and are confident that it will become a helpful—and enjoyable—resource for all those seeking to enhance their kidney health wellbeing.

In this first issue, we have gathered a diverse range of articles, interviews, and informative features that cater to the interests and concerns of our readers. Living with kidney disease is a deeply personal journey, and we recognize that everyone's needs and goals are unique. Therefore, we are endeavoring to make our magazine inclusive and accessible to all.

We also aim to foster a sense of community among our readers, and encourage you to share your thoughts, experiences, and success stories with us. Your feedback is invaluable as we strive to continually improve and tailor content to meet your needs. We are excited to embark on this kidney-health-focused adventure together. Thank you to all of our contributors for extending their expertise to this first issue.

Sincerely,

Andrea Rudy and Deborah Tucker
Managing Editors

harvest time!

Ingredients

1 tablespoon olive oil

1 small white onion, chopped

2 tablespoons chopped fresh ginger

4 large carrots, peeled and chopped

1 apple, peeled, cored, and chopped

8 ounces canned chickpeas, no added salt

3 teaspoons ground cinnamon

4 cups vegetable broth, no added salt

1.5 cups unsweetened plain almond milk

Directions

In a large pot over medium heat, heat the olive oil. Add the onion and ginger. Cook until the onion is soft and translucent, about 5 minutes.

Add the carrots, apple, chickpeas, cinnamon, and broth.

Simmer the soup until the vegetables are tender, about 15 minutes.

Remove from the heat and pour the soup into a blender. Add the almond milk and blend until smooth. Alternatively, use an immersion blender, and blend the vegetables and almond milk in the pot until smooth.

nothing says it's autumn like apple picking

carrot and apple soup

COMFORTING AND HEALTHY, STRAIGHT FROM KIDNEYCOMMUNITYKITCHEN.CA

more meatless Mondays for kidney health

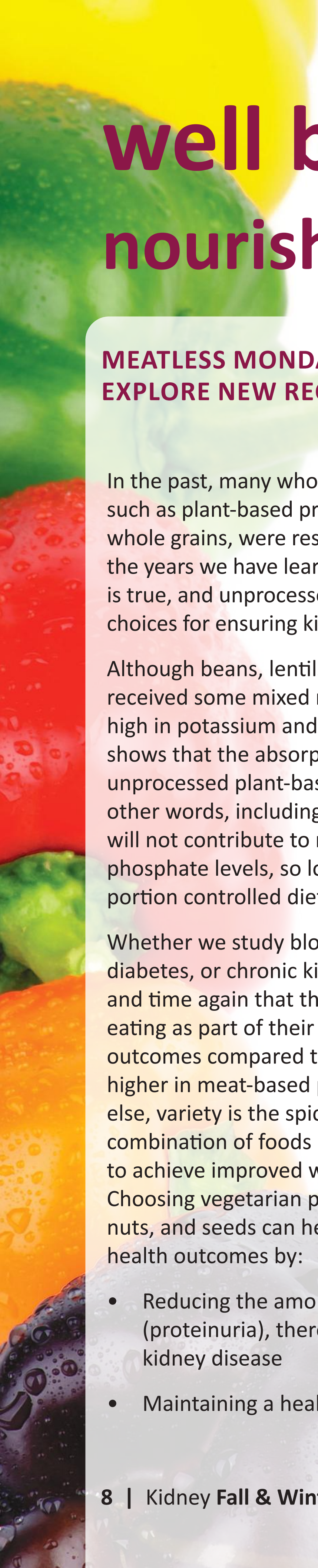
By Dani Renouf, RD, MSc, CDE

Food choices are a significant part of maintaining good kidney health and overall health. While there is plenty of information online, much of it is conflicting and so it can be a challenge to navigate all the messages that relate to nutrition and health to finally land on a diet that is flavourful, enjoyable, and nutritious.

VARIETY IS THE SPICE OF LIFE

Meatless Mondays encourage culinary exploration and creativity. From hearty lentil stews to colorful vegetable stir-fries, there is an abundance of delicious and nutritious options to explore. Added bonus? Meatless Mondays aren't only beneficial for us, they also help the environment.

meatless Mondays don't work? make it a meatless Wednesday



well balanced *and* tasty?

nourishing our kidneys

MEATLESS MONDAYS NOT ONLY HELP OUR KIDNEY HEALTH AND ENCOURAGE US TO EXPLORE NEW RECIPES, THEY CAN ALSO KEEP GROCERY BILLS DOWN.

In the past, many wholesome and nutrient-rich foods such as plant-based proteins, vegetables, fruits and whole grains, were restricted on a “kidney diet”. Over the years we have learned that, in fact, the opposite is true, and unprocessed, natural foods are the best choices for ensuring kidney health long term.

Although beans, lentils, and other legumes may have received some mixed reviews for being naturally high in potassium and phosphate, recent research shows that the absorption of these nutrients from unprocessed plant-based proteins is quite low. In other words, including these foods in your diet will not contribute to raising your potassium and phosphate levels, so long as you enjoy a balanced, portion controlled diet and use a variety of foods.

Whether we study blood pressure, heart health, diabetes, or chronic kidney disease, we see time and time again that those who include plant-based eating as part of their diet tend to have better health outcomes compared to individuals whose diets are higher in meat-based proteins. As with everything else, variety is the spice of life, and including a combination of foods in your diet is the best way to achieve improved wellbeing, health, and energy. Choosing vegetarian proteins found in beans, lentils, nuts, and seeds can help improve kidney-related health outcomes by:

- Reducing the amount of protein lost in urine (proteinuria), thereby slowing progression of kidney disease
- Maintaining a healthy weight and thereby improving blood pressure, blood sugar, and cholesterol
- Increasing fibre intake in the diet and preventing constipation for improved elimination of waste from the body
- Reducing the acid load on your kidneys

Try to limit processed vegetarian proteins (veggie burgers, miso, and salted nuts) and instead buy bulk beans, lentils, or chickpeas—soak them overnight, drain off the water, and add them to your favorite recipes. Unsalted nuts can be included in small amounts in most kidney-friendly diets, but portion control is important. Sprinkling of seeds in recipes is a great way of including these nutritious morsels, while watching potassium and phosphate levels at the same time.

Along with providing protein and other important vitamins and minerals, plant-based foods are also a significant source of fibre, which is an important component for digestive health. Avoiding constipation is an important aspect of controlling potassium levels, and enabling the body to remove waste more effectively through the bowel. Fibre is an important nutrient for the gut microbiome, which we are learning is a gateway to a healthier immune system. It also helps with fullness and weight management, and helps lower blood sugar levels in those who are living with diabetes.

Try this great recipe by Chef Ilan David Wright (opposite page).

**to ensure food safety, remember to fully cook lentils*

MIDDLE EASTERN CHICKPEA AND VEGETABLE STEW

Ingredients

2 tbsp	vegetable oil
1	medium eggplant, 1-inch dice
2	carrots, peeled, ½-inch dice
1	medium onion, thinly sliced
5	cloves garlic, finely chopped
2 tbsp	grated fresh ginger
2 tsp	sweet paprika
2 tsp	smoked paprika (optional)
1 tsp	cumin seed
2 tbsp	tomato paste
3 cups	water
1 cup	cauliflower, frozen florets
2	bell peppers, 1-inch dice
6 cups	no salt added canned chickpeas, rinsed and drained

Whole Wheat Couscous

5 cups	boiling water
2 ½ cups	whole wheat couscous
2 tsp	curry powder (optional)

Method

- Place dry couscous in a heat-proof bowl or pot and pour in boiling water. Cover tightly with plastic wrap or lid. Fluff with a fork after 15 minutes to break up any clumps.
- Heat medium pot with oil and fry garlic until slightly browned. Add eggplant and continue cooking until browning begins. Add onions and carrots and cook together for 3 minutes. Add ginger and spices and cook for 1 minute.
- Add tomato paste and water. Bring everything to a boil and gently simmer for 20 minutes, uncovered.
- When carrots and eggplant are tender, add peppers, cauliflower, and chickpeas. Simmer for approximately 10 minutes or until all vegetables are knife tender.

serves 10 (two cups per serving)

physical activity vs exercise

By Ryley Carr, Clinical Exercise Physiologist

Let's be honest, for some of us—maybe even many of us—setting aside time in our day for routine exercise is an effort in itself. Even if we aren't juggling jobs, children, grandchildren, errands and everything in between, getting on a treadmill for a prescribed amount of time may feel daunting. And for those of us with mobility issues, exercise can take on a whole new meaning. That's why this winter, we're embracing the concept of physical activity, which encompasses a broader range of movements that can be incorporated into our daily routines, and working it in through achievable amounts when we can.

Physical activity involves incorporating physical movements into our everyday lives, such as walking, taking the stairs instead of the elevator, grocery shopping or playing with children or pets. These simple activities may not seem as rigorous as a dedicated exercise routine, but they offer numerous benefits. Like saving our pennies for a rainy day, every little bit adds up and as a result it increases energy expenditure, improves cardiovascular health, enhances mobility and flexibility, and reduces the risk of chronic diseases like obesity, diabetes, kidney disease, and heart disease.

We aren't giving up on exercise *totally* this winter. Afterall, structured exercise routines, such as aerobics, yoga (or chair yoga and chair aerobics for those with limited mobility), and strength training help to build muscle strength, enhance bone density, reduce stress and anxiety, and promote better sleep. Furthermore, exercise often offers a sense of accomplishment and satisfaction, as individuals can set goals and track their progress over time. Whatever you choose to do, finding activities we genuinely enjoy sets us up for greater success. A scheduled weeknight walk with a friend, a game of indoor tennis, gentle snowshoeing, or dusting off the bike for a peddle up and down the street can all be fun things to look forward to and help maintain long-term commitment.

"Before being diagnosed with kidney disease, I was always up doing something. I am a high energy person," says Dan Reddy, who is also kidney patient. "Now that I go to the renal clinic at the hospital three nights a week for my dialysis treatment, I am much more tired. But my wife still makes sure I build movement into my daily routine through walking and gardening and it helps a lot."

Kidney patient, Brenda Brown, echoes what the benefits of movement are and how it transformed her life. "When I was on dialysis I found I was tired, and the thought of moving, let alone exercising, unappealing and at times impossible. Then I discovered yoga and was able to incorporate yoga into my dialysis runs. It changed my life truly and set me on a new path. Today I am very active, including teaching yoga and participating in the Kidney March."

While both physical activity and exercise have their merits, finding the right balance between the two is crucial for overall wellbeing. Incorporating regular exercise sessions into your weekly routine ensures that you reap the specific benefits associated with structured physical activity.

Stand instead of sitting while texting or talking on the phone

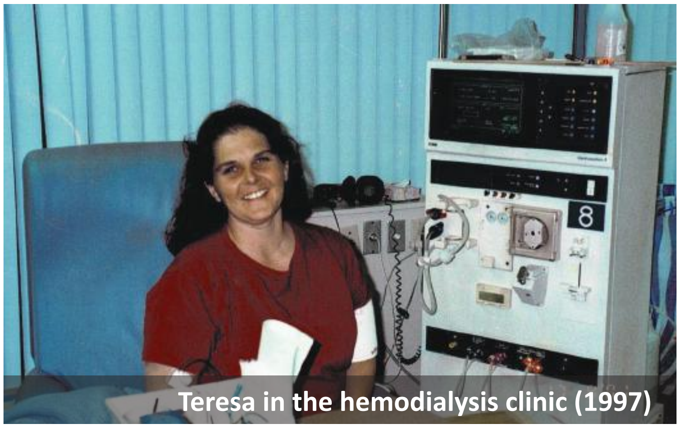
- Take stairs instead of elevator where available
- Take regular breaks from the computer or consider a standing desk
- Join a walking group
- Handwash pots and pans instead of using the dishwasher
- Move the garbage can away from your desk
- Do thirty seconds of toe touches or arm stretches every hour
- Tap your feet or scrunch your toes while reading
- Park farther away from the store
- Stand on one foot while brushing your teeth

physical activity tips

strength in connection

By Teresa Atkinson

LIVING WITH CKD CAN BE A CHALLENGING JOURNEY, BUT CONNECTING WITH OTHERS WITH SIMILAR EXPERIENCES CAN MAKE A REMARKABLE DIFFERENCE.


Teresa in the hemodialysis clinic (1997)

When I was first diagnosed with kidney disease, I remember thinking I don't look sick, this will be easy, I don't need to share this with anyone. What I didn't realize at the time was how beneficial sharing can be. Many kidney patients face anxiety, stress, and a reduced quality of life due to the uncertainties associated with kidney disease.

The impact of Chronic Kidney Disease (CKD) sometimes means that making time for social connections can take a back seat. But what I've experienced, along with others, is that living with kidney disease can feel lonely and those within our social network—be it our partners or friends—often struggle to understand what we are going through, especially if we look healthy. This is where connecting with people who share similar experiences is incredibly helpful to break this sense of isolation.

It all changed for me when after I was asked to refill supplies for the Kidney Foundation's Coffee Cart Program at the local clinic where I dialyzed. In joining others in the local Kidney Foundation Chapter I realized the value of sharing experiences with others. Connecting with peers has had such a powerful impact on my life; I was hooked, and as a result of my volunteering, my connections have grown.

For most of us, the pandemic changed the way we interact and I for one am still working on rebuilding my social connections.

A few volunteer friends wanted to create a safe space online to connect, so with the support of The Kidney Foundation we created a private Facebook Group—a place where we could talk about anything kidney and share lived experiences. Patients, their care partners, living donors, health care clinicians and researchers are all members. After all, there is no cure, CKD is with us for life, and we all become a family.


Search for Kidney Friends Circle on Facebook

Teresa (center) and kidney community friends Vivian (left) and Annick (right)

With everyone working online, I was also able to become more active in research projects as a patient partner with Can-SOLVE CKD Network and BC Renal. As fellow participant Nancy Verdin said, “Being a patient partner is where I can truly make an impact on the future of kidney disease.”

Working with researchers really made me feel like I was able to contribute to kidney research in some way, which in time might be able to change the face of kidney disease for future patients.

Then I had the opportunity to join the Kidney Wellness Hub team and I’ve greatly enjoyed connecting with more individuals who have similar lived experiences, like my friend Patrick. He told me:

> ***“Connecting with somebody who understands what you are truly going through is very important and was an important factor in my recovery and overall experience living with kidney disease.”***

And I whole heartily agree. By reaching out and engaging with peers on a similar journey, you can find a community that understands what you are going through and helps support you on your kidney journey.

Five ways I am safely rebuilding my social connections

1. Staying connected online
2. Talking with peers like you
3. Meeting up in small groups
4. Wearing a mask if uncomfortable in a crowd
5. Volunteering with kidney organizations

up close and personal with Sylvie Charbonneau

By Deborah Tucker

Sylvie shares her family's story with kidney disease, her experience as a living donor, and highlights from her term as National Board President along with her hopes for the future.

Sylvie, thank you so much for taking the time to share your story. How did you and your family learn your son, Benoit, had kidney disease?

To be honest the news came as a complete shock. There was no history of kidney disease in the family. We were always an active family—my husband, Andre, and myself—and I always felt blessed that I had two healthy children Benoit (we call him Ben), and his younger sister Melanie.

Our story started back in 2004, when Ben, 22, was at Sherbrooke University and out of the blue one day he felt very unwell when at a sports practice. So unwell that his friends took him to the ER. There he discovered his blood pressure was extremely high, and the doctor at the time suggested he should see his GP based on his blood test results, and that he should have his kidneys tested. But you know kids at that age, they think they're invincible and when he began to feel better, he just moved on with his life.

Fast forward three or four years, and he was back in the ER, once again feeling very unwell. After many tests, he learned his kidney function was at 25% and was told he had kidney disease.

Ben immediately came home and told us that he had some very bad news, that he had kidney disease and eventually would need to go on dialysis or get a kidney transplant. To this day we don't know exactly what type of kidney disease Ben has, just that it's a rare form and is congenital.

How did life change for Ben after his diagnosis with kidney disease?

It was a bit of a roller coaster ride for all of us, but especially for Ben. A huge change and challenge for my son was the new diet he was recommended to follow.* Everything had to be measured. Ben was over six feet tall and weighed 200 pounds, he

**Diet restrictions have changed over the years and can be different from patient to patient.*

was active in sports and was only allowed about 7 ounces of protein per day. He loves food and the changes were very hard for him.

But a real wakeup call came maybe a year after his diagnosis. His girlfriend at the time called us and said Ben was in a hospital in Montreal; his potassium level was so high that he was at risk of having a heart attack. I think it was at that moment we realized the seriousness of this disease. Fortunately, they were able to treat him, so he didn't have to go on dialysis.

But after that Ben was very anxious about everything he ate. If he or I were not doing the cooking, he would look at his plate of food and worry. I remember one day we were at a restaurant celebrating my father-in-law's birthday and when Ben got his meal, he said he wasn't feeling well after a few bites. We had to go to the hospital, but it turned out to be just a panic attack. This happened more than once.

Sylvie, you mentioned how kidney disease impacted Ben beyond just physical symptoms. Can you elaborate on this?

We learned along our journey that kidney disease is not just physical symptoms.

It can cause anxiety, as I mentioned with Ben's diet, but can also cause feelings of isolation. Ben did not want anyone to know he was sick and so for many years did not tell his friends or colleagues at work. His reason was simple: he did not want anyone to pity him.

He also wanted life to be as normal as possible. His days became very routine. He would go to work, come home and have a small meal, go to bed, and start the next day. He was very tired, but he did not miss a day of work except for doctor appointments.

The only person who knew he was waiting for a kidney transplant was his boss. But even though he wanted to normalize his life, it was not normal. He had to give up water polo as he got closer to his surgery date. His doctor wanted him to be extra safe and conserve his energy for the operation, so he told his friends he was injured and couldn't play anymore.

But it can be really lonely and difficult mentally if you don't open up and talk about your challenges and share how you feel.

I'm the total opposite to Ben in that way. When I decided to put my name forward as his kidney donor, everybody around me knew about it. I had my own consulting business at the time and my colleagues and clients all knew. Through talking to people, I learned a colleague's daughter had a kidney transplant when she was fourteen, and another who gave a kidney to his niece. Talking to others in similar situations really helped. But I was not the one sick, so I totally understand that people don't want others to look at them differently. But on the flip side, I think talking and sharing can help one cope and not feel alone.

Tell us about your journey towards becoming a living kidney donor.

The first time I heard about live kidney donation was on a radio interview around 2007. That changed everything for me. I told Ben that I wanted to give him my kidney. Together we embarked on an educational journey to learn about the kidney donation process. My first lesson was patience.

The hardest part of the whole process was the waiting. Waiting to go through the tests, waiting to see if I was a match, waiting for surgery dates.

But I focused on what I could do, including becoming as healthy as I could. I became very aware of my health through the process. I remember telling my husband that I've never been tested so thoroughly, so if I have something I'll know about it. It was good to have all that information about your health. And eventually we got the news we wanted. I was a match for Ben, and we got our surgery dates.

Describe how the transplant and recovery process unfolded for both you and Ben.

It was December of 2012. Another cold day in Montreal. But for us, it was the day we had been waiting for, for a long time. When Ben woke up after his surgery, he was very excited and so happy that it was done. He still had to go through the recovery process of course, but after about four weeks he asked his doctor if he could return to work because he was tired of being at home doing nothing. He returned to work five weeks post-surgery, with instructions to take it slowly. Ben was a bit anxious to return to his swimming and his beloved water polo, but when he did, he couldn't believe the difference in his energy levels and began to realize just how sick he was before the transplant. Incredible he told me. Like a transformation.

For me, the impact of the surgery was minimal. I was back in the office in January just four weeks after the holidays. I didn't have my full energy back and didn't ski every weekend that winter, but by spring I was on my bike just like before the surgery. I was 56 when I had the surgery and quite honestly never at any point since then have I said I don't feel well and it's due to donating my kidney.

One thing I'm always surprised by when I share our story is that almost every time I'm asked if I need a special diet. Do I have to take any medications? What's the impact on my life? And my answer is no special diet, no medications, no impact on my life except for that recovery period. That's it. People are amazed to see that you can do such a good thing for somebody else with very minimal impact on yourself. People don't know that.

Speaking of sharing your story, how did an opportunity with a local newspaper also become an important milestone for Ben on his journey with kidney disease?

I had a friend who was working for a local newspaper and they were running a special edition just around Christmas before our surgery to talk about gifts that you can give to teenagers, to your wife, to your husband. And they wanted to also talk about the gift of life. She asked me if she could write something about our story for the front page of the newspaper.

> ***I believe anytime we can raise awareness about the importance of organ donation it's a very good thing.***

I asked Ben and he was okay to do the story, but I told him he should tell his friends so they don't learn about his illness from an article. This was a big deal as Ben had been silent for so long about his disease. Finally, about a week before the paper was due to be published, he called one of his friends from his water polo team and shared. His friend had had no idea and was shocked. He told the whole team for Ben, who gained an instant support network. After his surgery, he went back to the pool just to say "hi" and everybody got out of the pool and clapped and cheered for him. They were amazed, happy, and he felt really good in that moment. He realized that talking about his story was a good thing.

Can you talk about Ben's involvement with the Transplant Games and what these Games meant to him? *(Read more about the Transplant Games on pages 28-29.)*

Ben celebrating gold in the 200-metre freestyle

One of Ben's goals after the transplant was to participate in the World Transplant Games in the swimming competitions, as he's a swimmer, which he did in Argentina in August 2015. My husband and I decided to join him. But the Transplant Games became far more than just a competition in sporting events. I will never forget when Ben said to us that being at the Games made him realize he was not alone. Yes he had the support of his family and friends which was very important, but at the Games he met others who had the same issues as him, and he was able to talk about diet, training, and medication impact.

"Here," he said, "I am not an exception, I fit in." He was so happy and so energized. Encouraged, I think, as he realized that there were other stories like his, but also stories tougher than his. Because of that bond between these people, he made friends for life.

You have also become a passionate participant in the Transplant Games. Can you share with us how you became involved?

We attended many other Games both in Canada and internationally. But I think that first Games we attended in Argentina opened my eyes too. We met people with remarkable stories of recovery. Kidney, heart, and liver transplant recipients, including a

20-year-old girl who had two weeks to live before she got her liver transplant. We watched them train and compete. I told my husband, look at us. We're healthy and we're just sitting and watching. It doesn't make sense, so I said we have to do more. Then at the Málaga Games, they announced that they were also accepting living donors as participants. I told my son and he said the real question is not can you participate, it's will you do it? And I said, "Oh, challenge accepted!" So, in Perth, I got my chance to compete, and participated in 5km run, 100-metre sprint and the 50-metre freestyle swim. Ben came back from the Perth Games with five medals and a world record in the 200-metre freestyle swim in the age category 40-49. I was so proud of him. We will be attending the Canadian Games in Ottawa in August 2024. I've already started my training and want to try the racewalking event. I'm also planning to go to the 2025 Games in Germany. Because of all this, I believe I'm healthier and I'm in better shape than I was ten years ago.

It seems Ben's community of support was there for him, especially when he experienced some very challenging periods with his health.

Yes, for sure. Luckily for Ben, he had a group of friends who really got it. During COVID, he went through a tough period. He had severe pneumonia and spent 18 days in hospital. He was discouraged. Some of his Transplant Games friends live in Ontario and I reached out to let them know Ben was sick and feeling down. Within five minutes they were calling him and wanting to drive to Montreal to visit him.

After he battled pneumonia, in 2021 Ben got more bad news. His kidney was failing and he'd have to go on dialysis. That was really hard. He was put on the transplant list but was told it could be a long wait because he is highly sensitized. And then a miracle happened, in January 2022, after just seven months he got a call from Transplant Quebec about a potential donor. It was a match. It was a successful surgery and we were blessed again. He's doing very well now. He's 41 today, living in Montreal with his girlfriend, and working in IT at Concordia University.

But his friends really helped get him through. It's this community he has such a strong bond with because they understand what each other is going through. I don't know how else I could express it, but I've rarely seen such strong bonds between people. And that shows that, you know, signing your consent for organ donation, talking to your family about your consent is so important, so, so important.

Sylvie at the Scotiabank Charity Challenge supporting The Kidney Foundation

As a living donor, do you have your own community of support?

My community is The Kidney Foundation. When I started my testing to be a living donor in 2012, I asked the nurse with the Transplant Program if I want to get involved, if I want to help, where should I go? That's when I learned about the Foundation and the Quebec Branch, and over ten years later I'm still involved. I've met so many inspiring and good people through this experience. My first volunteer event was the Kidney Walk in Montreal. My team raised over $10,000 in our first year; I was so proud of my colleagues.

You are a long-time volunteer, and have assumed several leadership roles with The Kidney Foundation. Tell us about these roles and why they were important to you.

I cannot be just a little involved in something, I have to give it my everything.

After volunteering with the Quebec Branch starting, I think in 2013, I was then asked if I would be interested in joining the Board of Directors and was elected in 2016. I was excited to do this as it gave me an opportunity to get more involved and understand where we could have influence to make things better for kidney patients. After two years serving as a director on the Board, I was elected the Quebec Branch President. The executive director and I took this opportunity to meet with heads of all the political parties in Quebec to talk about what we were doing at The Kidney Foundation and what would make the system better for patients.

As president, I had a seat at the National Board, and in 2019 I was approached to put my name on the slate to serve as the National Board president. And I don't know if you remember what happened in March of 2020, I certainly do and was elected right in the middle of the pandemic. So, it was a challenging period.

But thanks to the hard work of all the senior management, staff and volunteers across the country, we got through it, and were still able to provide the much-needed resources and supports to kidney patients. I guess if there was anything positive out of the pandemic, it was that technology provided more opportunities to collaborate from coast to coast.

I believe if there's a good idea, then let's not duplicate—let's share. I'm a knitter. I knit every day and I knit socks and mitts and beanies and all kinds of things that I sell at Christmas markets, and I give back the money to The Kidney Foundation. In Manitoba they were doing kidney care boxes for new patients on dialysis and needed 100 pairs of slippers. I was asked if I would help, so I mobilized my sister and a few friends and we just did it. It was such a great idea they had in Manitoba, that we're now doing a pilot project for the Quebec Branch.

As National Board president, you helped to steer the Foundation through a pandemic, embracing what we can do together as one team, as "One Foundation". What's your hope for future?

The Kidney Foundation is about to celebrate 60 years. That is amazing and so many important milestones have been achieved. But there's always more work to do. We are building strong platforms, and growing awareness and visibility across the country. People need to know how serious this disease is, who's at risk, the importance of organ donation and the role of The Kidney Foundation, including who we are and all the good things we're doing to help patients and the kidney community.

Any final words of wisdom?

Whether you are a patient, a caregiver or a kidney donor, my advice is to talk to someone who gets it. The Kidney Foundation can connect you to another living donor so you can talk to someone who has been through the process.

As a living donor, I think you get so much more than you give. I know I am not alone in thinking that.

One thing that is going to stay in my mind forever is the morning after Ben's transplant surgery, when my son came into my room to see me, just to say thank you mom. Later I went to see him in his room, and he was having his first apple juice in three years. Something he had missed dearly. I thought to myself, it's because he has my kidney that he can now drink apple juice. My God, the feeling after is indescribable. I don't know what words to use. It's an extraordinary human experience.

newly diagnosed? information is power

Contributors: Micheli Bevilacqua, MD, FRCPC, MHA, CHE and Andrea Rudy

Four million people in Canada are living with kidney disease, and the number of people living with end-stage kidney disease has grown 29% since 2012. More than 53,000 Canadians are currently living with end-stage kidney disease, for which there is no cure.*

Receiving a diagnosis of kidney disease can be overwhelming and, expectedly, will lead to many questions. Armed with answers and information, however, can return a sense of control and even help delay or possibly avoid kidney failure requiring dialysis or transplantation. Symptoms may not appear until permanent damage has occurred, so it's incredibly important to understand the stage you've been diagnosed at and what your options are.

While damaged kidneys don't heal, preventing or slowing down further damage remains critical. In most cases, being able to do so depends on maintaining a healthy lifestyle and managing other medical conditions.

In the early stages of chronic kidney disease, lifestyle changes, such as getting more exercise, stopping smoking and cutting down on sodium, managing other medical conditions, and taking medications as directed by your doctor may be all the treatment needed to slow the damage to the kidneys. People often go for many years, or all of their life, without needing other forms of treatment. The kidneys are so good at doing their job that even diseased kidneys can keep you healthy for a long time. Damage to the kidneys may be slowed down or even stopped if you take steps to preserve your kidney function.

Having a trusted source for information—both the latest resources and a place to enter personal case details—is helpful for managing kidney disease. The Kidney Foundation of Canada provides the *Living* *with Reduced Kidney Function* manual, which is updated regularly, for all newly diagnosed patients across the country. This comprehensive resource contains background material on kidneys and CKD, information on how to support your kidney health, manage medication and diet, develop a personal care plan, and places to enter your personal health details.

Every case is different, so the more you know, the more you can feel empowered.

More than one in four new end-stage kidney disease patients are late diagnoses, which means they started dialysis only a few months after diagnosis and first seeing a nephrologist. The damage can occur over many years or happen very quickly, depending on the source, with diabetes and high blood pressure as the two leading causes. If you have diabetes or high blood pressure, the best way to halt or delay end-stage renal disease is to properly manage these health conditions. Doctors can diagnosis kidney disease with blood and urine tests, a kidney ultrasound and possibly a kidney biopsy or other specialized tests.

What does the future hold?

Recent advancements in both slowing progression of chronic kidney disease and the treatment of end-stage kidney disease have drastically improved the long-term outlook for people living with this condition. With treatment, patients can lead fruitful, high-quality lives for many years. The success rate for kidney transplants is high, and for those on a transplant waitlist, being on dialysis can help them live a life as close to normal as possible for many years.

Research has shown that people have better health outcomes when they are involved in seeking answers to many of their questions for themselves, by understanding their disease, participating in decision-making and playing an active role in their treatment and care.

Learning you have kidney disease can be overwhelming on many fronts. Patients have shared that being prepared for their appointment with their doctor or healthcare team has helped to give them a sense of comfort and control. Bring a list of any medications and supplements you are taking for your doctor to review. It can also be helpful to make a list of questions before your appointment. Below are a few examples.

- Why don’t I have any symptoms?
- When should I contact a healthcare provider?
- What signs should I watch for, and at what point should I contact you about my symptoms?
- Are there things I can do to help maintain my kidney function?

(source: My Kidneys, My Health)

*data provided by The Kidney Foundation of Canada

breaking language barriers

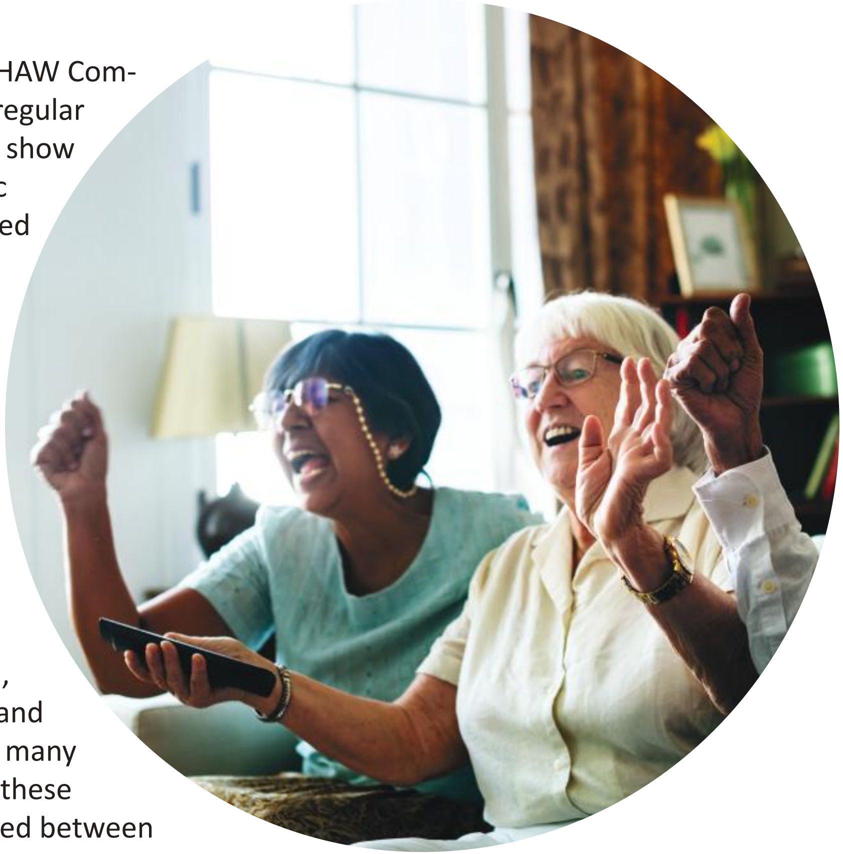
By Barb Valentine

In an era dominated by digital media and global connectivity, local TV programming continues to hold a significant place in our society, connecting communities, amplifying local voices, and fostering a sense of belonging.

After reviewing a few pilot episodes, in 2016 SHAW Community TV offered the BC and Yukon Branch a regular time slot for its newly created kidney health tv show Kidney PLUGGED IN, aimed at increasing public awareness about kidney health in a light-hearted format. The 30-minute TV show includes patient stories, interviews with renal experts and the latest in kidney research to name a few, and is still going strong seven years later.

BREAKING LANGUAGE BARRIERS

One of PLUGGED IN's ongoing objectives is to bring awareness to those who may not realize they are at risk of developing kidney disease. In addition to being over the age of 50, kidney disease also affects people of Aboriginal, Asian, South Asian, Pacific Island, African, Caribbean and Hispanic descent in a greater proportion. With many members of our local communities falling into these risk categories, a natural synergy was established between Kidney PLUGGED IN and SHAW Multicultural Channel.



lights, camera, action!

Multicultural programming is extremely important in our communities where language barriers can often create a sense of isolation for new immigrants and first-generation Canadians. By providing access to educational shows like Kidney PLUGGED IN, not only do we bring awareness to populations that would benefit from the content, but we also bring a sense of community and connection across our platform.

Jim Reis
Coordinating Producer, Multicultural Channel

In 2018, the show's programming expanded from English only to include multicultural episodes filmed in multiple languages including Mandarin, Cantonese, Punjabi, Korean, Vietnamese, and French. For the past few years, PLUGGED IN has aired a Chinese New Year's series—subtitled or hosted in Mandarin—every January. These episodes have featured the Chinese Renal Association, the Jun Hua Chinese Opera, special Chinese New Year kidney-healthy cooking, and other community groups.

Check your local Shaw Multicultural Channel, Shaw Spotlight, or Shaw Direct TV listings for days and times the show airs in your community.

Forgot to PVR an episode?

Catch it on the Kidney PLUGGED IN YouTube channel youtube.com/@KidneyPLUGGEDIN.

taking care of care partners

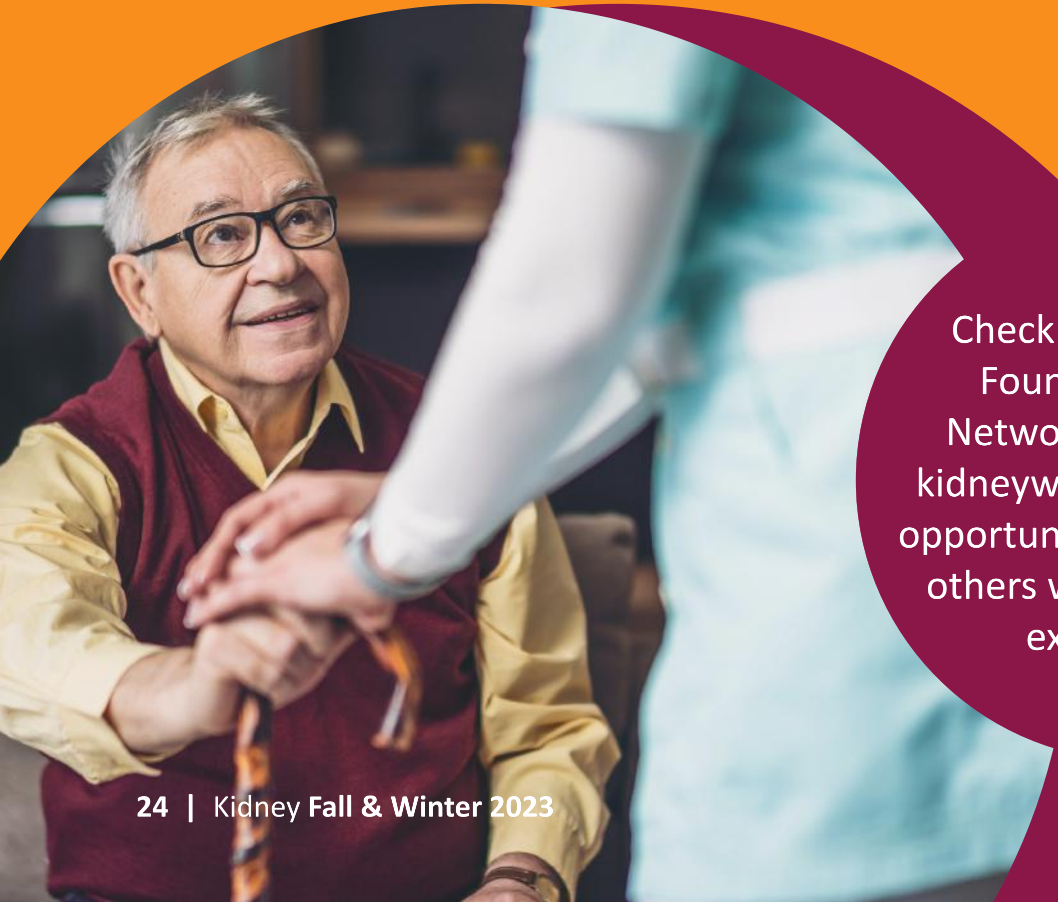
By meghan gorosh, RSW, SEP

It is crucial to remember that behind most care recipients, a dedicated care partner—someone fundamental in supporting and ensuring the well-being of those for whom they care—is silently working in the background. Whether tending to physical needs, providing emotional support, or managing administrative tasks, care partners shoulder immense responsibility. Often experiencing physical, mental, and emotional stress, the risk of fatigue is all too real when care partner concerns, needs, and well-being are not supported.

Caregiving brings a wide range of emotions, from joy, connection, and satisfaction to guilt, anger, and grief. Respite care is essential, as is community care. Temporary relief provided by professional services or other family members can allow care partners to take regular breaks, helping to mitigate fatigue and injury, and maintain overall well-being.

To ensure care partners receive the support they deserve, it's essential to implement multifaceted measures. Awareness campaigns can shed light on the challenges they face, reducing stigma and encouraging open conversations. Accessible mental health services tailored to their needs can provide a safe space to express their emotions and seek guidance. Respite care is a vital component, allowing care partners to take breaks and recharge. This could involve temporary relief provided by trained volunteers or professionals, offering care partners the chance to tend to their own needs without guilt.

According to Statistics Canada, more than one in four Canadians are caregivers, providing care for family members or friends with long-term conditions. Financial support mechanisms, including subsidies for caregiving expenses, tax breaks and caregiver employment insurance



Check out the Kidney Foundation's Peer Networking Groups at kidneywellnesshub.ca for opportunities to connect to others with shared lived experiences.

CARE PARTNERS ARE UNSUNG HEROES EMBODYING COMPASSION, SELFLESSNESS, AND PROVIDING NECESSARY SUPPORT TO THOSE IN NEED. WHILE THEIR DEDICATION OFTEN GOES UNNOTICED, THEIR IMPACT IS IMMEASURABLE.

benefits, may assist with financial strain. In addition, education and training opportunities empower care partners with necessary skills and knowledge on available resources, tools and community health services. Regional government health websites are an excellent place to start.

Open and honest communication between care partners, care recipients, and healthcare professionals is vital for effective caregiving. Regular discussions about expectations, concerns, and the overall care plan can foster a collaborative approach, reducing stress and improving the quality of care. To help reduce stress, it's important to take time, as care partner Sharon Recalma knows.

"Being a care partner to my husband who was on dialysis during COVID was an especially difficult period, and it led me to look for ways to help deal with the added stress," says Sharon Recalma.

"I had been belly dancing for a few years when COVID hit and our close community had to find new and inventive ways to continue to connect and support each other. Although belly dancing is something I do just for me, I love it and am constantly amazed by the difference it makes to my physical and mental state. Not only have I met a new community of friends, after each class I feel more energized and now dance is a part of my weekly routine. Dancing helps me to be more focused and engaged to support my husband and look after our day-to-day needs."

Talking to other care partners who have shared lived experiences can also help. Ultimately, a society that cares for its care partners nurtures compassion. By fostering a culture that values their contributions, we ensure the well-being of those who tirelessly care for others, promoting a healthier and more empathetic community as a whole.

watch for these signs of care partner fatigue

- Feeling overwhelmed or constantly worried
- Feeling tired often
- Getting too much sleep or not enough sleep
- Gaining or losing weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy
- Feeling sad
- Having frequent headaches, bodily pain or other physical problems
- Abusing alcohol or drugs, including prescription medications

Source: Mayo Clinic

it’s a match!

milestone for the kidney paired donation program

By Kate Chong

Canada passed a significant milestone this past spring as the 1000th kidney transplant was made through the Kidney Paired Donation (KPD) program. Since 2009, KPD has given people the chance to become a living kidney donor if they are not a match for a loved one in need, while finding their loved one a kidney from someone else in Canada in the same situation. Run by Canadian Blood Services, potential donor information is entered into the Canadian Transplant Register and then records are searched to find a possible match elsewhere in the country. Donors from incompatible pairs are swapped to create compatible pairs.

KPD works with BC Transplant and Yukon Organ Donation Program, which oversee all transplants in the respective regions. The program is also open to people willing to donate a kidney without a specific candidate in mind. These donors can start a domino effect, with their one donation triggering several transplants. In fact, as of June, 699 of the 1020 KPD matched transplants were given through the domino exchange started by non-directed donors. Visit the Canadian Blood Services website for details on registering in the program.

Being a living organ donor should not be a financial burden. For those who step forward to be a living donor, the Living Organ Donor Expense Reimbursement Program (LODERP) offered through the BCY Branch may reimburse eligible expenses related to organ donation, including travel, accommodations, parking, meals and loss of income related to your assessment and donation of an organ (kidney or liver).

*data from Canadian Blood Services

go team Canada!

amazing 59 medals at the 2023 World Transplant Games

By Andrea Rudy

Since 1978, the World Transplant Games Federation has held sporting events that celebrate transplantation and the gift of life, in addition to helping raise awareness of organ donation. The level of sport seen every year demonstrates the degree of health and fitness that can be achieved post-transplant.

This April, Team Canada put in an outstanding performance at the World Transplant Games in Perth, Australia. Athletes and teams from 45 countries participated in 17 sports over the week-long competition. In total Canada won 59 medals—21 gold, 18 silver, 20 bronze—and amazingly set eight new world records. In addition, Canadians won several overall awards, including Grey Brett (Ontario) who won male Athlete of the Year, Elizabeth Black, who won the women's Living Donor Athlete Award, and Carli Bekkering (Alberta), who brought home the Family Donor Athlete Award in the women's category. BC was well represented at the Games by Elizabeth Black, Brenda Brown, Kathleen Fleming, Addison McArthur, and Ken McLeod. Each athlete participated in a number of events, and all made it to the podium.

What stuck out for Kathleen, however, was the comradery between athletes from all nations. "One of the most compelling aspects of the Games was the almost immediate connection participants from around the world had with one another." Agreeing, Brenda adds, "You introduce yourself first by country, name, then organ. Quite funny, but amazing how many years of second life you are living or have given. There is a fun competitive spirit, but an electricity about the Games you can feel everywhere you go."

One evening Kathleen won't forget is the Games dinner where countries performed on stage, showcasing their culture through a variety of songs, dances, and skits. "It was a truly engaging experience but the country that rocked Culture Night was India. When India took to the stage they owned it!" The event really underscored the international connectivity for which the World Transplant Games is famous.

Brenda spoke to the age range of competitors, which in itself was inspiring—from the sportsmanship of older athletes in the pool swimming their best, encouraged by a cheering crowd, to watching the young kids jumping and running at the athletics events, knowing that each one was there thanks to an organ donor and a choice.

Interested but want to stay local? There are also Transplant Games held in Canada. In 2024, the Canadian Transplant Games will be held in Ottawa, and promise to have an amazing turnout of athletes from across the country. If you are considering a trip to Italy soon, be sure to check out the 2024 World Transplant Winter Games, which will be hosted in Bormio, Italy, March 3-8. Visit wtgf.org for more information.

Kathleen Fleming and Brenda Brown

Team Canada owned the podium in women's 100m sprint (from left: Elizabeth Black, Kathleen Fleming, Sylvie Charbonneau)

Team Canada Swim Team

"More than 1500 people were in Perth living their best possible lives through sport, because more than 1500 other people were selfless enough to give them the greatest gift of all, a second chance at living."

Brenda Brown

"As a living donor, it was incredibly rewarding to witness the numerous athletes who might have faced difficulty getting out of bed before undergoing transplantation, but who could now travel and compete. It was a profound experience."

Kathleen Fleming

Subscriptions

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